

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN7645001

Exhibits: WITN7645002

Dated: 22 February 2023

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B ANONYMOUS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 02 February 2023.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1968 and my address is GRO-B.
2. I am married and have two children and three step-children. I work for GRO-B County Council. I am the fourth child of five. The eldest sibling is GRO-B who I understand is going to provide a statement to the Inquiry. GRO-B then GRO-B: B2 who has provided a statement GRO-B followed by GRO-B: B1 and GRO-B.
3. I intend to speak about my brother, B1 who very sadly died of AIDS in 1991 aged 28 as a result of receiving infected factor VIII.

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blood products. There were almost five years between [B1] and me. My perspective therefore is that of a younger brother who for the early period of his infection, after his diagnosis was not that involved and so I have to piece together the parts that I can recall with what I subsequently learned from the family when I became older. For this reason, my memory of the dates and/or years is not that clear. Therefore, I will try as hard as I can to relate the nature of [B1]'s illness, how the illness affected him, his premature death and the impact this had on him, my parents, my siblings and me. I think my sister [GRO-B] the eldest, will be able to provide more details in her statement as she was closer in age to [B1].

4. I should also point out that my brother [B2] was infected with hepatitis C. Though I will touch on his infection, I have very little in the way of detail and so I refer the reader to his statement for a more comprehensive account.
5. The anonymity process has been explained to me. Whilst I am happy for my name to be on my statement, I have chosen to remain anonymous to protect my brother [B2]'s anonymity, which I understand was his choice when he gave his statement. I will also make mention of [B1]'s widow. I understand that she has elected not to give a statement to the Inquiry and may wish that her identity not to be publicly aired.

Section 2. How Affected

6. [B1] was born on [GRO-B] 1963. My parents were not aware that there was haemophilia in the family. [B1] had his tonsils removed when he was 7 or 8 but he didn't stop bleeding. The doctors told my parents that he might die as a result of the blood loss.
7. Ultimately, one of the doctors decided to test [B1] for haemophilia and they discovered that he was positive. This enabled them to treat [B1] to stop the bleeding. [B1] was diagnosed with mild haemophilia.

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8. After this discovery, myself and my other siblings were tested for haemophilia. In addition to B1 B2 was also found to be a mild haemophiliac, though I was negative. My sisters GRO-B and GRO-B were found to be haemophilia carriers.
9. I realise now that I was very fortunate to avoid the haemophilia gene. My two sisters both have sons and thankfully none of them have haemophilia. So, the family haemophilia gene should hopefully end there.
10. I remember B1 and B2 were both active lads, despite their haemophilia diagnoses. Their haemophilia was such that if they had a knock or a fall, they would have to go to hospital to receive factor VIII treatment. I don't ever recall seeing them administer the factor VIII at home. My guess is that B1 was diagnosed around 1971 when I was about 3.
11. B1 was the most active and physical of the two and consequently he had to go to hospital more frequently. B1 was a physical and sporty kid who enjoyed canoeing, playing cricket and football.
12. At a guess, I would say that B1 would go to hospital to receive factor VIII maybe twice a year. I believe that both his and B2's treatment was received at either the Royal or the Queen Alexandra Hospital in Portsmouth.
13. I think I was aged 14 when I first learnt of B1's HIV diagnosis. I was definitely in senior school and I would guess this was around 1982. One day, Mum took me aside and told me that B1 had received a blood transfusion that had problems with it and as a result he had been diagnosed with HIV.
14. I remember B1 not wanting me and GRO-B his two youngest siblings, to know about his HIV. He thought we were too young to be

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told. For some years I never dared mention it to B1 because I didn't know if he knew that I knew. Even so, GRO-B and I knew that we weren't to discuss B1's HIV with anyone, especially at school and I never did. This was made very clear to us, primarily because of the stigma associated with it but also because B1 was someone who never wanted to be pitied.

15. At the time of his HIV diagnosis, B1 was working for a children's GRO-B in Wales. He loved this job assisting and supervising kids on adventure trips and activities. B1 was mad keen about canoeing and rock climbing, so to get this job was just ideal for him. This would have been after finishing his A-levels and following him dropping out of Plymouth Polytechnic after 6 months. I think he must have been 19 or 20.
16. I understand that B1 had suffered a knock during one of the activities that had necessitated factor VIII treatment. B1 went to a local hospital, at which time his blood was tested. As a result of this B1 was told he had HIV.
17. I know nothing about how B1 received his HIV diagnosis. I cannot say which hospital it was in Wales, where B1 was working.
18. Although I didn't know it at the time, B1 attempted to commit suicide fairly soon, within a day or so after receiving his HIV diagnosis.
19. I understand that B1 had walked to a remote spot by a river and slashed his wrists. Although in a secluded area, a stranger had found him and was able to raise the alarm. I cannot say much more about it except that I believe that B1 had intended to kill himself because he would not have expected to have been discovered.
20. I often try and put myself in B1's shoes. I can't imagine how he must have felt. He was a healthy, fit and popular young man with his whole

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life ahead of him. Then, from nowhere, he had received what was effectively a death sentence. This was completely devastating for him.

21. In spite of his HIV diagnosis, [B1] never wanted to be treated like someone who was ill. He hated the idea of people viewing him in that way. He just wanted to carry on as normal, and that is what he, and we, did. In many ways, this improved our relationship. I didn't know how long he had left and so time was precious.
22. At some stage, [B1] met his wife [GRO-B] through work. He had briefly studied computing at Plymouth Polytechnic and he got a job working for a global IT company where they met. It is difficult to recall exactly when this was, but it was in the mid 1980s.
23. [GRO-B] and [B1] were a perfect match for each other. [B1] told her about his HIV status early in their relationship and she was fully accepting of this. They were both very happy together and they married within two years of meeting.
24. [B1]'s health did not deteriorate dramatically until the final two years of his life. I used to visit [B1] and [GRO-B] every few months and stay for the weekend. In his final two years, [B1]'s appearance deteriorated markedly. His face became gaunt and he lost a lot of weight and physical strength. He also became quite yellow, which leads me now to believe that he also had hepatitis. I cannot recall whether he was diagnosed with HCV.
25. I remember visiting [B1] one time and he offered me his triathlon bike. By this stage he knew he could never use it again. We went to his shed to see it but he did not have the strength to lift it out. He had become so weak. This was such a stark contrast to his earlier vitality and fitness. It was a big shock for me to witness this and brought it home to me that his inevitable and tragic demise had commenced.
26. At some stage I became aware that [B1]'s HIV had developed into AIDS. [B1] was having difficulties at work and it was becoming obvious

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that he was unwell. This forced him to have a difficult conversation with his employer, during which he broke down in tears and told them that he had AIDS.

27. B1 apologised to his employer, the large IT company, for not being honest with them about his health from the outset. B1's firm was incredibly understanding. They were accepting and supportive of his condition. I think they gave B1 some sort of medical retirement package, which was decent of them. They could have just terminated his employment because he had lied about his health to get the job.
28. Towards the end of B1's life, we as a family began to accept the inevitable. In the final year, 1991, I was going 'Interrailing' around Europe with a couple of friends. It was obvious that B1's health was in steep decline.
29. Whilst in Europe, I phoned B1 regularly to check up on him. At one time, I phoned home and learnt that B1 had been admitted to hospital. I asked my dad if I needed to come home, but Dad said that he had spoken to B1 and he wanted me to carry on enjoying myself. He didn't want to ruin my trip, which I find very emotional to think about now. It was so wonderfully thoughtful and caring of him. B1 never wanted us to pity him and he couldn't stand the idea of his illness affecting my holiday.
30. I recall hearing about B1 going to see the film, Terminator 2 which had just been released, so this was 1991. B2 took him to see it in the cinema. B1 needed a wheelchair to go out of the house by this time.
31. B1 said that the combination of the movie's production with all the special effects and the fact that he was on temazepam had made it an incredible experience.

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32. In August 1991, Mum and Dad went to visit [B1] at Basingstoke District Hospital with a couple of bottles of champagne. I think they thought it would be the last time they saw him, but remarkably [B1] pulled through.
33. When I returned to the UK from interrailing, [B1] was in hospital for the final time. I went to see him in Basingstoke District Hospital on his birthday, [GRO-B] 1991. He was noticeably yellow and his face was puffy. I remember giving him a chocolate orange as a bit of a joke present and thinking it was ridiculous because he was too ill to eat it. I took some time off work to be close to [B1] and to support [GRO-B] because I knew he didn't have long left.
34. [B1] died during the night of [GRO-B] 1991, just five days after his 28th birthday. No family members were with him at that time. My memory is that [GRO-B] got a call in the night to say that he was going and we, as I was staying at their house, went to the hospital but it was too late by the time.
35. The morning after he passed away, [GRO-B] and I had a conversation with the doctors about [B1]'s death certificate. [GRO-B] was worried that [B1]'s death certificate would evidence the fact that he had withheld his HIV/AIDS status from the life insurance company, which they had needed to secure the mortgage for their house. There had been no support for [B1] and [GRO-B] and this had been their only option to buy a property together.
36. The doctors were understanding of this and said they could record it in lots of ways. They said they would record his cause of death as a 'massive haemorrhage', which is what they did.
37. I enclose [B1]'s death certificate as exhibit **WITN7645002**, which records his cause of death as: '1a. Massive Gastrointestinal Haemorrhage'. Neither HIV, AIDS or HCV are mentioned.
38. I think it is a shame that it had to be this way, and if anything, it only adds to the secrecy about HIV/AIDS. But [B1] and [GRO-B] had no choice and

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were forced to withhold it from the life insurance company to obtain a property. There was apparently no means of financial support or advice for HIV/AIDS sufferers.

39. I remember [GRO-B] also faced difficulties arranging the funeral with the undertakers because of concerns about HIV/AIDS. This compounded the trauma she had suffered. There seemed to be a lot of hoops to jump through to arrange the funeral, probably relating to the myths about HIV/AIDS, which shows that stigma surrounded it even amongst funeral parlours.

Section 3. Other Infections

40. I believe that [B1] was also infected with hepatitis C ("HCV") as a result of receiving infected factor VIII blood products, although I cannot say for certain.

Section 4. Consent

41. I am not aware that [B1] was ever tested or treated without his consent. I seem to remember that [B1] knew from the outset that his HIV was a direct result of receiving infected factor VIII. I cannot say whether [B1] was ever informed of the risks of factor VIII being infected with HIV and/or HCV but it seems very unlikely that he would have been.

Section 5. Impact

42. [B1]'s premature death left a huge hole in all of our lives. It was a tragedy and it makes me so sad to think how he must have felt. [B1] knew that he had been given a death sentence when he was diagnosed with HIV, aged just 19.

43. At the time of [B1]'s diagnosis, there was hysteria about HIV/AIDS which resulted in a terrible stigma. [B1] was absolutely clear with all of us that he didn't want anyone to know. I don't think he felt shame, he just didn't want to be seen as an invalid.
44. The hysteria and misinformation surrounding AIDS was a terrible reflection on society as it was then. The way it was handled and portrayed by the government and the media was shameful. My Mum had been a nurse and this enabled her to cut through the myths and misconceptions about HIV. We all wanted to know what the reality was, and in my view the big media scaremongering campaigns were a poor way of relaying much needed information.
45. As a devout catholic, my mum leant heavily on her faith. She died of cancer in her 60s and during her demise, she told me that at least she would be close to [B1] again. Mum managed her grief through her faith but this never replaced the hole that [B1]'s death left. No parent ever expects to outlive their child. That alone is a tragedy.
46. It is incredibly difficult to quantify how losing [B1] has affected me. It is impossible to describe the void that his death created. I lost a brother who I loved and got on so well with. We were very different people but after he left home, we grew closer. I have no words to describe how it feels to have lost him then and for the years that followed.
47. [B1] was deprived of the joy of having his own children. He and [GRO-B] were unable to proceed with a family due his HIV infection. They used to say that they didn't want kids, but some years after [B1] died, [GRO-B] told me that they had dreamed of having children but just couldn't risk it. I should say that [GRO-B] did go on to have children.
48. After [B1] died, [GRO-B] re-married and moved to France. My father was still in contact with her and she always came to visit Dad when she was in the UK. I later learnt that [GRO-B] developed a dependency on alcohol,

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which I strongly believe was a large part due to the trauma of [B1]'s illness and death. She subsequently married twice more but has said that [B1] was the love of her life. I understand that [GRO-B] is unable to face discussing what happened to [B1] and she has chosen not to provide a statement due to the impact that retelling it would have on her mental state. This is partly why I have chosen to be anonymous, because I don't want her or anyone who knows her to read this but I believe that it is important to include something about the impact this has all had on her.

49. Towards the end of his life, [B1] was assigned a caseworker by the Terrence Higgins Trust. I don't know how this came to be arranged, though I suspect he was put in touch with them through the hospital. [B1]'s caseworker, [GRO-B] was a wonderful person who became like a family friend to us all.

50. [GRO-B] was there for [B1] to provide emotional support and advice regarding his HIV and AIDS. He was a huge help to [B1]. [GRO-B] was also openly gay, which may seem incidental and not worthy of mentioning however, they were vastly different times and it helped [B1] to deal with some of the anger and resentment he felt about how AIDS was portrayed by the media. It helped to remove the connotations about AIDS being the 'gay plague'. [GRO-B] was just a normal bloke who supported and helped [B1] come to terms with it.

51. We were never a particularly tactile or emotional family. We always loved and cared for each other but after [B1] passed away, we began to be more demonstrative. It made us re-assess and re-evaluate our lives. This is one good aspect to a terrible set of circumstances.

52. Revisiting these events has triggered emotions that have not been exposed for many years. I was determined to tell [B1]'s story because he doesn't have a voice, through no fault of his own. His infection with HIV through infected blood products, gave him a death sentence. [B1] had a beautiful wife and dreamed of having children. He would have

been a wonderful father. He had his whole life ahead of him, but this was cruelly taken away by his treatment with infected blood products.

Section 6. Treatment/Care/Support

53. I am not aware that [B1] faced any difficulties in obtaining treatment, care or support in consequence of his HIV infection.

54. I do not know if [B1] was ever offered counselling or psychological support in respect of his HIV infection. I do know that the family were not.

55. [B1]'s caseworker from the Terrence Higgins Trust acted as a source of information and support in many ways, but this was not provided by the NHS.

Section 7. Financial Assistance

56. I know nothing about the financial payments schemes available to victims of infected blood. I do have a vague memory of [GRO-B] receiving a £20,000 compensation payment but I don't know how or from whom this payment was made.

57. I have no interest in personally seeking financial compensation.

Section 8. Other Issues

58. My other brother [B2] [GRO-B] has also provided a statement to the Inquiry about his infection with HCV through infected factor VIII blood products. [B2] dealt with this privately and he is best placed to comment on the problems this entailed. [B2] has always been the most loveable person. He would do anything for anyone. [B2] suffered with depression and was in a dark place for a long time. His health problems pertaining

to his HCV infection have massively impacted him. The fact that he kept it so private and didn't talk about it has had a detrimental effect on him.

59. B2 has re-married now and seems to be in a much happier place. I am so glad to see this. He said at his recent wedding reception that he used to feel like he had nothing to live for. He had suffered in silence. This was so devastating to hear. Thankfully he is a revitalised person now and I hope his new marriage gives him the happiness that he deserves.

60. For many years, I kept B1's illness a secret from others, because that was what he had wanted. Now, I feel a responsibility to tell his story, because he doesn't otherwise have a voice.

61. Whilst I appreciate that the enquiry is now finally taking place, I cannot find the words to express my anger that successive governments have delayed this until now.

62. In the intervening decades many of those infected will have suffered, and in many cases, passed away without even their voices being heard. This has massively impacted those infected, their partners, parents, siblings, children and loved ones and we all feel that our voices, feelings and needs have been woefully and deliberately ignored.

63. While my brother was alive the only support he really received was from the (wonderful) Terrence Higgins Trust, without which his experience would have been even worse, if that is possible

64. Both during, and following his diagnosis, illness, decline eventual death we, his family, were never offered any form of counselling or support and have spent the decades since trying to find our way through and come to terms with, our feelings of unnecessary of loss, and never knowing the man our brother could, and should, have been able to become.

65. The years we had after the diagnosis were of course incredibly precious but the way the publicity was handled meant that there was an

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associated, though of course misplaced, shame associated with the disease, a disease which it would have been so easy to avoid had the necessary measures and checks been in place. I would ask the government accept the mistakes of the past, to offer an open and full apology and to ensure that all those involved, both directly and indirectly are offered all of the help and support now that should have been in place for all of these years.

66. Finally, I can never fully put into words our feelings of loss but hope that those we have lost, and those who continue to suffer have a voice and are treated with the respect that they deserve. I know we will never forget our brother and am just sad that our parents never had the opportunity to add their own words to this enquiry.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed

GRO-B

Dated

22/2/23